

Chapter 11

National Family Caregiver Support Program

11-1: Description of the National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) establishes an infrastructure of program resources and assistance for family caregivers and grandparents or other relative caregivers. The NFCSP in Tennessee shall be provided in accordance with Title III, Part E, of the Older Americans Act (OAA), as amended in 2006, and TCAD Program and Policy Manual. Grants to States, with State Plans approved under Section 307, shall pay for the Federal share of the cost of carrying out State programs to enable area agencies on aging or entities that such area agencies on aging contract with, to provide a multifaceted system of support services. The NFCSP shall be accessible and provided throughout each of the planning and service areas of Tennessee.

11-1-.01: Caregiver Definitions

The focus of NFCSP is the caregiver and provides a service delivery system that respond to the needs of the caregiver. **The caregiver is the client in the NFCSP program.** Caregivers include:

- (1) Family Caregivers
 - (a) Adult family members (age 18 years or older) or other adult informal caregivers providing care to adults age 60 and over.
 - (b) Adult family members or other adult informal caregivers providing care to individuals of any age with Alzheimer's disease and related disorders.
- (2) Grandparents and Relative Caregivers
 - (a) Grandparents, step-grandparents, or other relatives (including parents) age 55 and older providing care to adults, age 18 to 59, with disabilities. Disability refers to conditions attributable to mental or physical impairment or to a combination of mental and physical impairment that results in substantial functional limitations in one or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficient, cognition functioning, and emotional adjustment [see 42 USC 3002 (8)]

- (b) Grandparents, step-grandparents, or other relatives (not parents) age 55 or older providing care to children under the age of 18 years.
- (c) Grandparent and relative caregivers referred to in 11-1-.01 (2)(a) and (b) must also:
 - (i) live with a child that is not more than 18 years of age or is an individual with a disability (18-59 years of age with a disability).
 - (ii) be the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child.
 - (iii) has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally.

11-1-.02: Service Components

The Tennessee Commission on Aging and Disability (TCAD), working in partnership with the nine (9) Area Agencies on Aging and Disability (AAAD) and local community service providers, shall provide five (5) categories of services for caregivers. The number of activities/contacts/hours/sessions required for each of the 5 categories is indicated in parentheses. The categories are as follows:

(1) Information Services (1 activity)

This service for caregivers provides the public and individuals with information, resources, and services available to the individuals within their community. Information services are activities, such as but not limited to, disseminating publications and conducting media campaigns, directed to a large audience of current and potential caregivers.

(2) Access Assistance

(a) Information and Assistance (1 contact)

This service assists caregivers in obtaining access to the services and resources that are available within the community. To the maximum extent practicable, this service ensures that the individual receives the services needed by establishing adequate follow-up procedures.

(b) Care Management (1 hour)

This service provides assistance either in the form of access or care coordination in circumstances where the care recipient is experiencing diminished functioning capacities, personal conditions, or other characteristics which require the provision of services by formal service providers or family caregivers. Activities of case management include such practices as assessing needs, developing care plans, authorizing and coordinating services among providers, and providing follow-up and reassessment, as required.

(c) Outreach (1 contact)

This service provides intervention with individuals initiated by an agency or organization for the purpose of identifying potential caregivers and encouraging their use of existing services and benefits.

(3) Individual Counseling, Organization of Support Groups, and Caregiver Training (1 session)

This service is provided to assist the caregivers in the areas of health, nutrition, and financial literacy in order to make decisions and solve problems related to their caregiving roles. The services include:

(a) Individual Counseling

Caregiving can be very stressful, both physically and emotionally. Individual counseling allows the caregiver the opportunity to discuss issues related to caregiving such as, but not limited to, identifying signs of caregiver burnout or stress; coping with the emotions such as frustration, feelings of inadequacy, and depression; and, above all, taking care of one's self. A licensed professional counselor should provide individual counseling; however, if a licensed professional counselor is not available, a staff person qualified by training or experience can deliver the service if he/she is supervised by a counselor licensed by the State of Tennessee. The AAADs must have a Licensed Counselor or a counseling agency to which to make a referral if a caregiver is in need of an individual counseling. Licensure can be verified at <http://health.state.tn.us/Licensure/index.htm> through the Tennessee Department of Health. Licensure includes: Licensed Professional Counselor, Licensed Clinical Social Worker, Licensed Clinical Psychologist, or PhD.

(b) Support Groups

This service offers sessions that allow caregivers the opportunity to discuss their attitudes, feelings, and problem with input from other members of the group; attempt to achieve greater understanding and adjustment; and explore solutions to their problems.

(c) Caregiver Training

This service offers training/education that is designed to assist caregivers with acquiring knowledge and skills that will help them in providing care.

(4) Respite Care

This service offers temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for caregivers. Respite care may include:

- (a) in-home respite such as personal care, homemaker services, and sitter service;
- (b) respite in a non-residential program such as adult day care;
- (c) institutional respite provided by placing the care recipient in an institutional setting such as a nursing home for a short period of time as a respite service to the caregiver; and
- (d) summer camps for children.

Transportation of the care recipient to an adult day care center or similar program, such as transporting children to summer camp, may be part of the respite expense.

(5) Supplemental Services

This service is provided on a limited basis to complement the care provided by caregivers. Examples of supplemental services include, but not limited to, home modification, home-delivered meals, medical equipment and supplies, personal emergency response system (PERS), incontinence supplies, and assistive technology.

Supplemental services also include:

- (a) Legal assistance that includes counseling as well as training sessions on legal issues should be reported as a supplemental service.
- (b) Transportation to medical appointments would be a supplemental service.

11-1-.03: Priority

In providing services, priority shall be given to:

- (1) caregivers who are adults age 60 and over with the following conditions:
 - (a) greatest social need caused by non-economic factors which include physical and mental disabilities; language barriers; and cultural, social and geographic isolation (including racial or ethnic status) that restricts an individual's ability to perform normal daily tasks or threatens his/her capacity to live independently; and
 - (b) greatest economic need resulting from an income level at or below the poverty line (100%) as defined by the Office of Management and Budget and adjusted by the Secretary of Health and Human Services with particular attention to low-income adults age 60 and over who are providing care to adults age 60 and over.
- (2) adults age 60 and over providing care to individuals with severe disabilities, including children with severe disabilities;
- (3) family caregivers who provide care for adults age 60 and over with Alzheimer's disease and related disorders with neurological and organic brain dysfunction; and
- (4) grandparents or relative caregivers who provide care for children with severe disabilities.

11-1-.04: Eligibility

Information, assistance, and counseling can be provided to any caregiver, but Respite and Supplemental Services funded under the NFCSP can be provided only if the **care recipient** meets the definition of frail. Frail means an individual that is determined to be functionally impaired according to the following guidelines;

- (1) The care recipient is unable to perform at least two (2) Activities of Daily Living (ADL) without substantial human assistance, including verbal reminding, physical cueing, or supervision; and/or
- (2) The care recipient has a cognitive or other mental impairment that requires substantial supervision to prevent the individual from harming him/herself or others.

Any of the five (5) NFCSP service categories may be provided to grandparents, step-grandparents, and other older relative caregivers caring for a child. The child is not required to meet frail guidelines to receive services.

Non-citizens are eligible to receive services through the NFCSP. In accordance with AoA guidelines, non-citizens, regardless of the alien status, should not be banned from services authorized by the OAA and administered by the AoA based solely on their alien status.

11-1-.05: Funding Limitations

- (1) Caregiver services under the NFCSP shall not exceed a maximum of \$7,000 annually per caregiver. AAADs who provide adult day care services only to caregivers that exceed \$7,000 must have prior approval from TCAD.
- (2) The total maximum annual amount of funding per caregiver must not exceed \$7,000 regardless of the funding source including when individuals receive services from multiple funding sources. In rare cases where the caregiver has multiple care recipients and the cost to provide services to support the needs of the care recipient exceeds \$7,000 the AAAD can request that the care plans be reviewed by TCAD for approval to provide services above the \$7,000.
- (3) Reimbursement for in-home services such as personal care, homemaker, home delivered meals and respite shall not exceed the OAA rate of reimbursement (See HCBS chapter for reimbursement rates).
- (4) AAADs shall not use more than twenty percent (20%) of its award to provide supplemental services. Supplemental services are flexible enhancements to caregiver support programs designed for the benefit of caregivers. Each AAAD can elect supplemental services based on local needs.

11-1-.06: Administrative Standards

Funds made available under the NFCSP shall supplement, not supplant, any Federal, State, or local funds expended by a State or unit of general purpose local government (including the AAAD) to provide services described in Title III, Part E, Section 373 of the Older Americans Act.

- (1) TCAD shall:
 - (a) designate a coordinator to implement and oversee program development of the NFCSP statewide.
 - (b) develop and maintain consistent standards and mechanisms for the NFCSP to be implemented statewide. These standards and mechanisms shall be used to assure the quality of services provided in accordance with the Older Americans Act, Administration of Aging regulations and policies, and TCAD policies and rules.
 - (c) develop standard individual assessment tools to be used by all AAADs.
 - (d) collect, maintain, and report information in State Reporting Tool (SRT).

- (e) provide training to the family caregiver program staff, as needed.
 - (f) provide technical assistance, as needed.
 - (g) assume quality assurance responsibilities for all caregiver programs to ensure compliance with standards, policies, and procedures of TCAD and the Older Americans Act.
- (2) At a minimum each AAAD shall:
- (a) publicize NFCSP services to ensure that individuals throughout the area know about the availability of the services.
 - (b) provide caregiver information and referral and screen individuals for caregiver support services.
 - (c) complete an in-home assessment on individuals whose screening indicates need for respite or supplemental services.
 - (d) arrange for the provision of individually needed family caregiver services directly and/or through local service providers.
 - (e) organize new and/or coordinate with existing caregiver support groups and caregiver training events.
 - (f) have a licensed professional counselor referral source to which caregivers can be referred for individual counseling, if needed.
 - (g) coordinate NFCSP with other programs and service systems serving individuals with disabilities.
 - (h) use trained volunteers to expand the provision of the five (5) service components.
 - (i) attend training planned or approved by TCAD.
 - (j) ensure appropriate program/financial reporting, billing, and budget reconciliation.
 - (k) negotiate contracts and provide quality assurance program implementation.
 - (l) compile, maintain, and report waiting lists of persons requesting caregiver services for which service is not available.
- (3) Service providers must:
- (a) be licensed in accordance with the regulations of the State. Service provider agencies providing in-home services (homemaker and personal care) must have a PSSA license or be licensed as a home health care agency by the Tennessee Department of Health

- (b) ensure services and units of service to be provided to individuals consistent with the Provider Authorization (Appendix E), where applicable
- (c) begin services within five (5) working days of the receipt of the Provider Authorization (Appendix E), where applicable
- (d) keep documentation of all contact with or on the behalf of the caregiver and/or care recipient and ensure that the assigned task identified in the Provider Checklist is carried out
- (e) keep documentation of each service provided with each visit, which includes a service rendered checklist that is signed by the individual and the worker
- (f) have methods and procedures in place for the collection and reporting of individual specific data, including but not limited to rosters, invoices, and daily logs and provide to the AAAD by the 10th day of the month following the month being reported.

11-1-.07: Consumer’s Right to Self-Determination

- (a) All adult individuals have a right to choose how they will live, as well as where they will live, as long as they are competent to make that decision and able to understand the consequences of their actions.
- (b) All adult individuals are presumed legally competent unless they have been deemed incompetent by a court.
- (c) It is essential to encourage the individual to live in an environment or situation that is safe. The NFCSP is not expected to assist an individual that chooses to continue to live in a situation that is unsafe or to make plans that are unrealistic and unsafe.
- (d) Reports to Adult Protective Services (APS) are mandated by state law when “any person” has reasonable cause to suspect abuse, neglect (including self-neglect), or financial exploitation. This includes neighbors, friends, relatives, doctors, dentists, caregiver, agency personnel, etc.
(Adult Protect Act T.C.A. 71-6-103(b) (1))

11-1-.08: Service Coordination

The Family Caregiver Coordinator/Options Counselor will provide service coordination whether it is in the form of access to services or care coordination to the caregiver to relieve caregiver burden they may experience in providing care to their loved ones.

Service coordination supports information sharing among agencies/organizations, service providers, types and levels of service, service sites, and timeframes to ensure that the individual's needs and preferences are achieved and that services are efficient and of high quality. Activities of service coordination include assessing needs, developing care plans, authorizing services, arranging services, coordinating the provision of services, follow-up and reassessment. Service coordination ensures non-duplication of services by identifying the services and/or service providers, the informal supports, and resources that are currently being utilized and/or provided to the individual.

11-1-.09: Assessment and Reassessment

If the screening indicates a caregiver's need for respite or supplemental services, the Caregiver Form 2010a (Appendix A) shall be completed. The most updated Social Assistance Management System Independent Living Assessment (SAMS ILA) (Appendix H) shall be completed on the care recipient that should include the following minimum sections:

- Section A – Intake/Assessment
- Section B – Individual Identification
- Section C – Demographics
- Section D – Caregiver Identification
- Section I – ADL/IADL and Other Limitations
- Section J – Nutrition Screening (If receiving a meal)

All assessments and reassessments shall be completed in a face-to-face interview in the home with the caregiver. Both the caregiver and the care recipient must sign the Signature Page (Appendix D). The care recipient must at a minimum sign the following:

- Privacy Practices and Individual Rights and Responsibilities
- Release of Information for Statistical Reporting
- Title VI
- Authorization for Referral for Services
- Client Agreement

If the care recipient is unable to sign or if the care recipient is a minor child, then the Signature Page can be signed by their Authorized Representative.

A reassessment is required at least annually; however, staff should be alerted for changes in a caregiver's condition or circumstances that may warrant a reassessment at an earlier date. Follow-up calls to the caregiver are recommended to be made semi-annually to ensure that the needs of the caregiver are being met. If follow-up calls are completed, they should be documented in a case note in the record of the caregiver.

Respite and Supplemental services provided through Title III-E must comply with policies and procedures of the service being provided. For example, a caregiver and/or care recipient that receives home-delivered meals through the NFCSP must comply with Nutrition guidelines.

If the caregiver is a Grandparent/Relative Caregiver of a minor child, then the caregiver would need to be assessed using the Caregiver Form 2010a (Appendix A) and the minor child would be assessed using the SAMS ILA (Appendix H) completing the following sections:

- Section A – Intake/Assessment
- Section B – Individual Identification
- Section C – Demographics
- Section D – Caregiver Identification

11-1-.10: Care Plan

The Options Counselor shall work with the caregiver to develop the care plan. The care plan specifies the types, frequency, and amount of in-home services provided to an individual based on a comprehensive assessment of the caregiver's needs. Service decisions must always be made in the best interest of the caregiver. The care plan must be discussed and developed with the participation of the caregiver ensuring the plan meets their needs. The care plan must be documented in the SAMS database.

(1) Care Plan Components

The care plan in the SAMS database must document at a minimum the following:

- (a) The specific support services needed including the frequency and duration of each service;
- (b) Start and end date of services;
- (c) Primary care manager (Options Counselor);

- (d) Allocated units of service;
 - (e) The name of the provider that will be providing the service; and,
 - (f) Cost of services
- (2) Changes to Care Plan
- Care Plans must be updated when a service is decreased, increased, discontinued, or a new service is added. Any changes to the Care Plan must be approved by the caregiver during an in-home visit or by phone. Changes to the Care Plan must be documented in a case note that the change was discussed and approved by the caregiver.
- A caregiver is considered in Interrupted Status if the care recipient does not receive services for thirty (30) days due to hospitalization or other causes. The Options Counselor should maintain regular contact with the caregiver during this time. The AAAD may terminate a caregiver from the program after the care recipient has been in Interrupted Status for thirty (30) days.
- (3) Care Plan Not Developed
- If any of the following conditions apply, a Care Plan shall not be developed:
- (a) if the caregiver notifies/tells the Options Counselor that he/she does not want to proceed with the development of the care plan;
 - (b) if the caregiver/care recipient refuses to release or provide information that is necessary to complete the assessment or develop the care plan; or
 - (c) if the services needed to support the caregiver are not available or the cost is above the \$7,000 limit to develop and carry out the care plan.

11-1-.11: Reporting Requirements

TCAD is required to submit the State Reporting Tool (SRT) on an annual basis that includes data on the NFCSP. The NFCSP is on the federal fiscal year, October 1 through September 30. The AAAD shall document all data in the SAMS database monthly by the 20th day of the following month for the previous month. Required reports must be submitted to TCAD according to the instructions, schedule, and form(s) provided. The year-end report should include data for the entire fiscal year.

Each AAAD shall maintain program data and individual information for each service provided through the NFCSP.

(1) The following demographic data for each caregiver must be entered into the SAMS database in order to qualify as a client of the program. An aggregate number may not be entered. The caregiver and the care recipient must be linked in SAMS. Demographic data should include the following:

- (i) Name
 - (ii) Address
 - (iii) Telephone number
 - (iv) Age
 - (v) Gender
 - (vi) Race/ethnicity
 - (viii) Rural status (usually determined by the AAAD based on address information)
 - (ix) Name and relationship to the care recipient
 - (x) Optional: Cell phone number or Email address, if available
- (2) The only service that is excluded from entering demographic data is Group Information. For this service, an aggregate number can be entered.
- (3) For Individual Counseling, Support Groups, and Caregiver Training, a unit of service is equal to a session. Each caregiver will receive a unit of service for each session he/she attend.
- (4) Home-delivered meals served with Title III-E funds may be counted as a Nutrition Services Incentive Program (NSIP) eligible meal **if** the meal:
- (a) meets the requirements of the OAA (Title III-C);
 - (b) is served by an agency that has a grant or contract with TCAD or AAAD; and
 - (c) is served to an individual qualified for service under Title III of the OAA:
 - (i) care recipients, who are age 60 and over;
 - (ii) caregivers, who are age 60 or older; or
 - (iii) caregivers, regardless of age, that are the spouse of a care recipient who is age 60 or older.

11-1-.12: Long Distance Caregivers

There are two (2) types of long-distance caregivers:

- (1) The caregiver lives within the State of Tennessee and the care recipient lives in another State.

- (2) The caregiver lives in another State and the care recipient lives within the State of Tennessee.

Caregiver services may be provided to long distance caregivers whose care recipient resides within the State of Tennessee, if funds are available. However, the decision to provide Respite and Supplemental services to long distance caregivers will be done on a case-by-case basis and must be pre-approved by TCAD. Title III-B or Title III-C in-home services or state funding home and community-based services should be considered first if the care recipient is eligible to receive services under those programs. If the caregiver resides in Tennessee and the care recipient resides within another state, the Tennessee AAAD should make a referral to the AAA in the State where the care recipient lives.

11-1-.13: Volunteers

Each AAAD shall make use of trained volunteers to expand the provision of the five (5) service components. The AAAD should work in coordination with organizations that have experience in providing training, placement, and stipends for volunteers or participants (such as organizations carrying out Federal service programs administered by the Corporation for National and Community Service) in community service settings. Such programs include Senior Corps and AmeriCorps (VISTA).

11-1-.14: Background Checks

This program must be in compliance with the Background Check Chapter of the TCAD *Program and Policy Manual*.

11-1-.15: Cost Sharing and Voluntary Contribution Requirements

Cost sharing shall be at the discretion of the AAAD. However, if the AAAD chooses to implement cost share, then cost share should be calculated on the care recipient's income with the payment being the responsibility of the caregiver. (See the HCBS chapter for cost share standards.)

Voluntary contributions shall be allowed and may be solicited for all services for which funds are received under the Older Americans Act if the method of solicitation is noncoercive. Contributions shall be encouraged for individuals whose self-declared income is at or above 185 percent of the poverty line, at contribution levels based on the actual cost of services.